



Assessing the responsiveness of chronic disease care - Is the World Health Organization's concept of health system responsiveness applicable?



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ABSTRACT

The concept of health system responsiveness is an important dimension of health system performance assessment. Further efforts have been made in recent years to improve the analysis of responsiveness measurements, yet few studies have applied the responsiveness concept to the evaluation of specific health care delivery structures. The objective of this study was to test the World Health Organization's (WHO's) responsiveness concept for an application in the evaluation of chronic disease care. In September and October 2012 we conducted four focus groups of chronically ill people ($n = 38$) in Germany, in which participants discussed their experiences and expectations regarding health care. The data was analyzed deductively (on the basis of the WHO responsiveness concept) and inductively using directed content analysis. Ten themes related to health system responsiveness and one theme (*finances*) not directly related to health system responsiveness, but of high importance to the focus group participants, could be identified. Eight of the ten responsiveness themes are consistent with the WHO concept. Additionally, two new themes were identified: *trust* (consultation and treatment are not led by any motive other than the patients' wellbeing) and *coordination* (treatment involving different providers is coordinated and different actors communicate with each other). These findings indicate the suitability of the WHO responsiveness concept for the evaluation of chronic disease care. However, some amendments, in particular an extension of the concept to include the two domains *trust* and *coordination*, are necessary for a thorough assessment of the responsiveness of chronic disease care.

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1. Background

The responsiveness of a health system is considered as one of three intrinsic goals of health systems (World Health Organization, 2000) and has been described as “a key characteristic of effective health systems” (Coulter and Jenkinson, 2005, p. 355). It is defined as a measure of how well a health system meets the non-medical, legitimate expectations of a population in its interactions with the health system (Darby et al., 2000).

The World Health Organization (WHO) developed the concept of health system responsiveness and its operationalization, based on an extensive literature review that draws from a variety of disciplines (De Silva, 2000). It is a concept focusing on patients' experiences during actual contact with the health care system and is,

thus, less dependent on patients' expectations than, for example, patient satisfaction instruments (Busse et al., 2012). With the aim to measure responsiveness across countries, the WHO reduced the number of the concept's domains to a common set of eight, which are valid for all health systems (Valentine et al., 2003). These can further be categorized into two major domains:

- (i) “respect-for-persons”: consisting of the domains *dignity* (being treated with respect), *autonomy* (involvement in decision-making), *confidentiality* (personal data is kept confidential), and *communication* (the provider listens carefully and explains things clearly) and
- (ii) “client-orientation”: consisting of the domains *choice* (possibility to choose between different providers), *prompt attention* (getting fast care in emergencies, short waiting times), *quality of basic amenities* (cleanliness of the facility, seating, fresh air), and *social support* (access to social networks during inpatient care) (Valentine et al., 2008).

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The WHO responsiveness instrument was used, among others, within the Multi-country Survey Study on Health and Health System's Responsiveness (MCSS) 2000/2001 (Üstün et al., 2001) and the World Health Survey 2002 (Üstün et al., 2003) and its psychometric properties were tested using the MCSS and World Health Survey 2002 data (Valentine et al., 2007; Valentine et al., 2009). Further efforts have been made in recent years to improve the analysis of responsiveness measurements (Rice et al., 2011; Robone et al., 2011; Sirven et al., 2011). Nevertheless, most studies measuring responsiveness comprehensively focus on differences between countries (e.g. Sirven et al., 2011). Few studies have applied the responsiveness concept for the evaluation of specific health care delivery structures, such as delivery care, or specific subgroups of the population (Bramsfeld et al., 2007b; Liabsuetrakul et al., 2012). Hence, the applicability of responsiveness instruments to subfields of health systems remains hardly explored.

To our knowledge, the responsiveness concept has not been explicitly tested for an application in chronic disease care so far, except for the special case of mental health care (Bramsfeld et al., 2007b; Forouzan et al., 2011). For numerous reasons the appropriateness of the responsiveness concept for chronic disease care is highly relevant for a thorough assessment of health system performance:

First, assessing the responsiveness of a health care system without taking into account the specific needs of chronically ill people may lead to results that do not adequately reflect the health system's responsiveness for such patients. With the high and growing number of chronically ill people in the majority of countries (Busse et al., 2010), a high number of health care users would not be adequately included in the performance assessment. Second, the inclusion of chronically ill people in health systems performance assessment is of high value, as chronically ill people are considered to be extensive users of health care services and, therefore, to be experts in rating health care delivery structures (Blendon et al., 2003). And finally, although the responsiveness of a health system focuses on non-medical aspects of health, it is assumed to influence care-seeking behavior and compliance, creating improved, more open interactions between patients and their health care providers (Jones et al., 2011; Williams, 1994) which can be considered key factors in successful chronic disease care (Busse et al., 2010).

The objective of our study was to test the applicability of the core responsiveness domains defined by the WHO for the assessment of chronic disease care. We aimed to answer the following questions: Are the WHO responsiveness domains relevant for the chronically ill? Are further domains needed to provide a comprehensive measurement of the responsiveness of chronic disease care?

2. Data and method

We applied focus group methodology to gather information on patients' expectations regarding health services in general and to review the WHO responsiveness concept and its operationalization for chronic disease care within the German health care system. We decided to use focus groups because we were interested in what participants think and how they express their experiences and expectations regarding health care to one another. Focus groups have been reported to be suitable for research questions of this kind (Morgan, 1996). Additionally, focus groups have been used before and have proved appropriate to test and generate items for questionnaires (Barbour, 2005; Kirchberger et al., 2009; O'Brien, 1993).

For participation in the focus groups, we exclusively recruited chronically ill people. We did not differentiate between different

chronic diseases or other factors (such as age, sex or disease severity) because we wanted to facilitate a broad discussion and we assumed the shared experience of chronic disease to be strong enough to achieve compatibility (Morgan and Scannell, 1998).

We started with recruiting participants for four focus groups, with the option to conduct additional focus groups if data saturation was not achieved. Ten persons were recruited for each group, using a multistage recruitment procedure. In the first stage, we advertised our focus groups using self-help groups for chronically ill people located in Berlin and a newspaper advertisement in a regional Berlin newspaper offering 25€ for participating. Secondly, interested persons who contacted us were asked screening questions. Thirdly, eligible persons (individuals who were chronically ill and who had sufficient knowledge of the German language) were invited to participate in one of the four focus groups.

The four focus groups were conducted in September and October 2012. All groups were conducted in the same facilities in Berlin and were moderated and co-moderated by the same two researchers. A manual was developed for the moderation. The discussion comprised four thematic sections divided into two parts split by a 20 min break (Fig. 1).

In the first part, participants were asked to talk about very positive and negative experiences they have had with their personal health care. In the second main part (after the break), the discussion was more focused: expectations were phrased based on the aforementioned experiences, clustered into categories and finally visualized by the moderator. When these categories were discussed, the moderator used the WHO wording that matched the responsiveness concept, i.e. expectations regarding waiting times were clustered into the category *prompt attention* (we applied the German translation according to the MCSS questionnaire (Üstün et al., 2001)). Using the WHO wording had the advantage of examining whether the wording was intuitively understandable. When the participants told the moderator that the derived categories represent all of their personal health care related experiences, the moderator introduced any WHO responsiveness domain that had not yet been covered in the discussion by naming the respective keyword (e.g. *confidentiality*) and asking the participants if they had related experiences. At the end of the discussion every participant was asked to select the three categories they believed were the most important for their personal health care. All participants filled in a short socio-demographic questionnaire at the end of the focus groups.

The focus groups were audio-recorded and transcribed verbatim with the consent of the focus group participants. An assistant

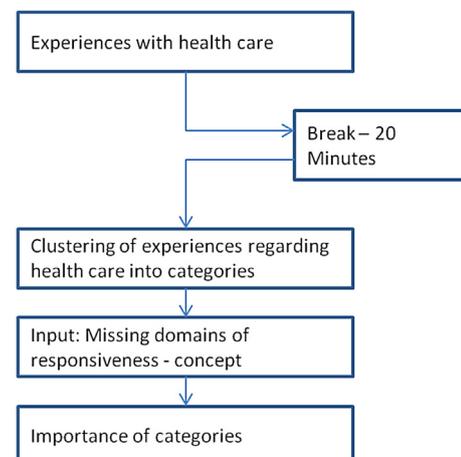


Fig. 1. Guideline for focus groups.

recorded the order of speakers in order to be able to allocate the statements to the different participants. Anonymization was ensured by calling the participants only by their first names during the discussion and replacing all names with numbers in the transcription process. Participants were fully informed about the aim of the research project and the focus group discussions. Participants were not put under risk at any point of the study, had the right to refuse to answer or to leave the discussion. Written informed consent was received from all participants. Based on these facts and the regulations of the responsible ethical review board it was decided that an ethical approval was not required for this part of the study.

Consistent with the aim of our study, we analyzed the data material using directed content analysis which, according to Hsieh and Shannon (2005), aims “to validate or extend conceptually a theoretical framework or theory” (Hsieh and Shannon, 2005, p.1281). Hence, a coding framework was developed that was partially deductive and partially inductive. The WHO responsiveness domains were used to categorize deductively. New emerging themes that did not fit into the existing WHO domains were categorized inductively. The unit of analysis was a theme, so text passages ranging from a single word to a whole paragraph were coded. The software Atlas.ti was used to facilitate the coding process.

To enhance the quality and validity of the analysis, two researchers conducted the coding independently. After coding the transcript of the first focus group, the coding framework was discussed and further refined. Subsequently, the transcripts of all groups were coded using the refined framework. Finally, the results from the coding with the refined framework from both researchers were compared and discussed. We chose this approach of data analysis because it has been reported to improve the quality and consistency of coding (Barbour, 2001; Plummer-D’Amato, 2008). Furthermore, it has already been successfully applied in analyzing focus groups (Moretti et al., 2011).

3. Results

3.1. Group and participant characteristics

Four focus groups with a total of 38 participants were conducted. In the first three groups, all of the invited ten persons participated. In the fourth group, two persons did not take part. The duration of the focus group discussions ranged from approximately 115–136 min including a 20 min break. The participants’ characteristics are presented in Table 1.

The age ranged between 30 and 76 years, with a mean of 56.5 years. The majority of the participants were women (68%). 36 of the 38 participants were insured under the statutory health insurance; only two participants were privately insured. All participants were chronically ill and the majority suffered from more than one disease. Most frequently the participants had disorders related to the circulatory system, the musculoskeletal system and/or the endocrine system. The participants had 12.8 doctors’ consultations on average within the last 12 months; 16 of 38 participants had an overnight stay at a hospital within the last 12 months with an average length of stay of 12 days.

3.2. Group discussions

The discussions revealed a variety of experiences and expectations regarding health care services. Overall, they could be divided into 11 themes. Table 2 displays the identified themes and their subthemes. Eight of the themes are very close to the WHO responsiveness domains and are named accordingly. Two of the themes (*trust* and *coordination*) are related to health system

Table 1
Participants’ characteristics.

Characteristics	Group 1	Group 2	Group 3	Group 4	Total
Number of participants	10	10	10	8	38
Age in years					
Mean	55.4	62	55.9	51.9	56.5
Min–max	32–70	42–71	45–65	30–76	30–76
Women/men (n)	7/3	7/3	5/5	7/1	26/12
Multimorbid (more than one disease; n)	9	8	8	7	32
Statutory/private health insurance (n)	10/0	9/1	9/1	8/0	36/2
Enrolled in DMP (n)	4	8	3	1	16
Participant in self-help group (n)	2	6	6	1	15
Doctor consultation within last 12 months (n)	10	10	10	8	38
Number of doctors’ consultations (last 12 months)					
Mean	19.3	10.1	10.4	12.5	12.8
Min–max	5–60	4–20	1–20	4–30	1–60
Overnight stays in hospital within last 12 months (n)	3	5	5	3	16
Number of nights stayed in hospital (last 12 months)					
Mean	2.3	8.8	25.4	5.7	12.2
Min–max	1–4	4–14	5–50	3–10	1–50
Employment status (n)					
Fulltime employed	0	1	2	1	4
Part-time employed	0	0	1	2	3
Student	0	0	0	1	1
Unemployed	3	1	2	0	6
Disability pension	3	2	2	1	8
Old-age pension	4	4	3	3	14
Education (n)					
Graduation after 9 school years	4	2	1	0	7
Graduation after 10 school years	4	3	3	6	16
Graduation after 13 school years (A-levels)	1	2	2	2	7
Graduation from university	1	3	3	0	7
Missing	0	0	1	0	1

responsiveness but had not been covered by the WHO domains. One theme (*finances*) was highly relevant for the participants and therefore has been included in this analysis, although it is usually not seen as a part of health system responsiveness (Murray and Frenk, 2000).

The themes and their subthemes are described below. The themes related to health system responsiveness are clustered into the two major domains “respect-for-persons” and “client-orientation”. Example statements for each theme are provided in Table 3.

3.2.1. Respect-for-persons

Dignity: Respectful treatment was discussed in all four groups and was considered an important part of health service delivery. Participants expect to be treated with empathy and friendliness by physicians and nurses, as well as by other personnel in health care services (e.g. doctor’s receptionist). The participants also expect to receive the full attention of the physician during their appointment and expect the physician not to focus solely on their single disease but to see and treat them as a whole person. The following statement illustrates the desire of the participants to be treated as an individual: “You want to get the feeling that you are treated as an individual person and not as a number. And you expect that they ask you: ‘How are you?’ [...] For example, at the medical practice, the doctor comes in and only asks: ‘What can I do for you? Do you need a prescription?’ That is so impersonal.” [Group 4, Part 1, Participant D7].

Finally, the participants expressed that all of these expectations should be fulfilled regardless of the patients’ type of insurance (private vs. statutory health insurance), age, sex or other factors.

Table 2
Themes and subthemes identified using directed content analysis.

Theme	Subthemes
Dignity	Being treated friendly (by physicians, nurses and other personnel) Being treated with empathy (by physicians, nurses and other personnel) Receiving full attention of the physician during treatment To be seen as a whole person Equality in respectful treatment between different patient groups
Autonomy	Involvement in decision-making process
Confidentiality	Data security Possibility to talk in private to the physician, the receptionist and others
Communication	Timely Easy to understand Time to ask questions Provision of informational material
Trust	Consultation in patients' interest (physician is not led by other motives) Treatment in patients' interest (physician is not led by other motives)
Choice	Possibility to choose between different providers Possibility to change the provider Possibility to stay with the same provider over a longer time period Equality in choice between different patient groups
Prompt attention	Waiting time for an appointment Waiting time in the waiting room Waiting time in case of an emergency Equality in waiting times between different patient groups
Basic amenities	Cleanliness Sufficient furnishing Sufficient sanitary facilities Quality of food
Social support	Access to private networks during hospital stay Professional social support, e.g. after discharge from the hospital
Coordination	Coordination between different providers Coordination of patients' course of treatment
Finances ^a	Co-payments and practice fee

^a The theme of finances is not a part of health system responsiveness.

Autonomy: In accordance with the WHO concept, the participants expected to be involved in the decision-making process. This basically meant that they want to be involved in the selection of their medications and that their previous experiences with medications and/or treatments be taken into account during this process.

Confidentiality: In three of the four groups, confidentiality was only discussed when it was brought to the attention of the participants by the moderator. Nevertheless, participants expressed the expectation to be able to talk in private to the physicians and receptionists and that their data were secured safely.

Communication: The following expectations were phrased based on the participants' experiences with communication: communication between patients and physicians (and other personnel) should be timely, i.e. the patient gets all relevant information as soon as possible, and the information is communicated in a way that is easy to understand for the patient and leaves enough time to ask questions. In addition, the participants phrased the expectation to receive printed informational material about certain diseases and treatment strategies. The following statement illustrates the experiences with insufficient communication: "For me it is an exceptional situation and I want to be informed about what is going on. I sometimes feel so uninformed about myself, about what they are doing with me. They just write something in their records [...] but then I still do not know what that means." [Group 1, Part 1, Participant A5].

Trust: During the group discussions, a number of participants reported experiences when they felt that they did not receive the appropriate treatment, medication or advice because their physicians were led by factors (e.g. budget) unrelated to patient well-being. Thus, the expectation was derived that health service users should be able to trust that they are receiving the best available treatment/consultation and that treatment decisions as well as consultations are not influenced by any other motive: "... but I felt that my family physician was financially influenced by different companies [...]. He always has products from these brands and then you are supposed to buy these products. And these products are very expensive [...]. And when you have problems, like me with neurodermatitis, you buy everything." [Group 4, Part 2, Participant D2].

3.2.2. Client-orientation

Choice: In all groups, participants expressed experiences concerning the free choice of a physician or hospital. Participants reported that they changed their physician or hospital when they felt unsatisfied with the treatment. They also phrased the expectation to be able to stay with the same physician continuously over a longer period of time. Again, as with the theme *dignity*, equality issues were discussed. Participants felt that patients with statutory health insurance had a smaller choice of physicians, especially specialists, than privately insured patients: "... and since then, a lot of physicians relocated their medical practice. There is now a higher density of physicians in the districts where a lot of privately insured people live than in those districts with only the statutorily health insured persons." [Group 3, Part 1, Participant C1].

Prompt attention: Participants' experiences ranged from long waiting times in an emergency to rather short waiting times for an appointment with a specialist. Participants also discussed problems of getting an appointment, or being able to reach a medical practice at all in order to either book or cancel an appointment. Experiences with waiting times at medical practices ranged from very long waiting times (4 h or more) to no wait at all.

The participants rated the importance of waiting times differently. Some participants expressed that they would accept long waiting times if other expectations were met (especially *dignity* and *communication*). Other participants were not willing to accept long waiting times at all. It was agreed upon by all participants that waiting times should be equal for all kind of patients (e.g. private insured vs. statutory health insured).

Basic amenities: Concerning the quality of basic amenities, the participants discussed the sanitary facilities, adequate furnishing, food and drinks, as well as the overall cleanliness of the facilities. "One is ill and you sometimes have to wait there for 4 h and they made so many appointments that there aren't even enough chairs in the waiting room." [Group 4, Part 1, Participant D3].

Social support: Social support was only mentioned in one group in Part 1. In all other discussion groups, participants only started discussing this topic when directed to it by the moderator. For most participants, social support was understood as professional social support, e.g. a patient is leaving the hospital and needs assistance at home. The participants felt that social support in terms of being able to stay connected to your social network while you are at the hospital (as defined by the WHO) is totally fulfilled in Germany.

Coordination: Participants expected two types of coordination. First of all, the coordination of the patient's course of treatment, e.g. the physician knows if certain tests have to be conducted regularly: "What I think is kind of funny, is that when I go to a doctor I have to tell the doctor: Could we please do this or that test? The doctor never says by himself: We should do a control NMRI." [Group 1, Part 1, Participant A9].

Table 3
Identified themes and example statements.

Theme	Example statement
Dignity	"Well I'm very satisfied with my family doctor, no matter how crowded it is, he always takes time for me. He closes the door, there are no phone calls, no-one comes in who could disturb. In that moment, you truly are the main person." [Group 3, Part 1, Participant C10]
Autonomy	"... that the doctor treats me as a responsible adult and does not make decisions without involving me but rather discusses things with me [...] and that he explains things to me [...] so that I feel that I have a choice if there are different treatment options." [Group 2, Part 2, Participant B4]
Confidentiality	"What comes to my mind is that when you are at the receptionist's desk and you need something, that there is a queue behind you and all of these persons can overhear you" [Group 1, Part 2, Participant A5]
Communication	"... and about the disease, they just confront you with a disease – lung fibrosis – which I never heard of before. And no one explains to you what it means." [Group 1, Part 2, Participant A7]
Trust	"Well a lot of the physicians only think economically. They only think about maximizing their income and hardly consider their patients' concerns and wishes. There are a lot of physicians who think in this way [...] who refuse to give medication, who insufficiently prescribe therapeutic aids, who do not prescribe treatments although they would have been necessary." [Group 3, Part 1, Participant C1]
Choice	"Well, I think you are – as a patient – of course responsible for yourself and to find out: a) what kind of disease do I suffer from, b) how will I handle it and what do I want to achieve in my disease management. Yes, and then I will of course try to find a physician or a hospital that meet my requirements." [Group 3, Part 1, Participant C8]
Prompt attention	"I have a statutory health insurance and I was very surprised by getting an appointment with the cardiologist within 6 days, which is very unusual [...] I thought I have to wait at least 2 month, but getting an appointment within 6 days was an extraordinary experience for me as a person with a statutory health insurance." [Group 2, Part 1, Participant B3]
Basic amenities	"I never thought that anything like this exists in Germany: That you are in a room without a toilet although you have enteropathy." [Group 1, Part 1, Participant A2]
Social support	"I know a lot of people who are old, have been to the hospital and don't get along on their own when they are at home. But when they are discharged from the hospital, no one cares how they will manage when they are back home" [Group 2, Part 2, Participant B4]
Coordination	"Well, but when your medical history becomes longer and longer, and you are consulting a new physician because you have a new medical problem, then you will always have to tell your whole medical history to your new physician." [Group 1, Part 2, Participant A2]
Finances ^a	"... but because of the co-payments one has to make, I can't use the medical services anymore [...] In the past I used to get massages because of my arthrosis [...] but today – with my pension – I just can't afford the co-payments anymore." [Group 4, Part 1, Participant D8]

^a The theme of finances is not a part of health system responsiveness.

Secondly, the participants expect that there be coordination between the different actors in the health care system. This was especially important for participants who visit different specialists. They expressed the wish for the different providers to communicate with each other in order to avoid double tests or divergent treatments, as well as to take the responsibility off the patient to know and be able to describe their complete and detailed medical history.

3.2.3. Financial aspects

Financial aspects of health care were discussed in all groups. This usually included the practice fee and (co-)payments for medications or treatments that are not (fully) covered by health insurance. Participants reported that they declined medications, treatments and appointments because they could not afford them. Thus, the participants phrased the expectation to receive all relevant medications and treatments without additional payment.

The themes discussed across the four groups as well as the participants' individual experiences with health care generally overlapped. This was the case for experiences shared in the first, structured part of the discussion and for those shared in the second part. As outlined in Table 4, all themes were discussed in all groups. In three groups the themes *confidentiality* and *social support* were only discussed when introduced by the moderator. With no new themes or aspects emerging after the analysis of two focus groups, we considered data saturation to be achieved.

3.3. Importance of categories

During the group discussions, the participants' experiences with health care were clustered into categories, representing the experiences and expectations participants had regarding their health care. At the end of the focus groups the participants were asked to name those categories that were most important to them. As the categories emerged within the group discussions, it has to be considered that they are not entirely consistent with the themes that evolved from the content analysis and are described above, e.g. during the focus group discussions the theme *trust* was seen as a

part of *dignity* and not as a distinct theme. Yet, the categories were very similar across all four groups.

At which frequency the different categories were selected as one of the three most important is displayed in Fig. 2. As some participants refused to name three categories, only 107 statements out of 114 possible statements were made. Overall, *dignity*, *prompt attention*, *communication*, and *autonomy* were selected most frequently as the most important category. The results were similar in the individual groups: *prompt attention*, *dignity* and *autonomy* were found important by at least three participants in each group (Fig. 3).

4. Discussion

The aim of this study was to test the applicability of the WHO responsiveness concept for an evaluation of chronic disease care. We conducted four focus groups of chronically ill people, the majority being extensive users of health care services, and discussed their experiences and expectations regarding health care.

We identified ten themes related to health system responsiveness, eight of which are closely related to the WHO responsiveness domains and two themes that were not covered by the WHO domains (*coordination* and *trust*). Consistent with the responsiveness literature (Valentine et al., 2003), our analysis showed that a clear distinction between the domains is only partially possible, particularly as some domains strongly influence each other, e.g. patients that accept very long waiting times for an appointment have a larger choice of providers than patients that do not accept long waiting times. Furthermore, in all groups the emerging theme of *finances* (Table 4) underlines how closely linked the concept of responsiveness is with other aspects of health system performance assessment.

4.1. WHO domains

The majority of the WHO responsiveness domains, except for social support and confidentiality, were extensively discussed in the first and open part of the group discussions. *Social support*, in terms of having access to your social network during a hospital stay,

Table 4
Covered themes by group and part of group.

Themes	Group 1		Group 2		Group 3		Group 4		Total	Total
	Part 1	Part 2	Part 1 + 2	Part 1						
Dignity	x	x	x	—	x	x	x	—	6	4
Autonomy	x	x	—	x	x	—	x	—	5	3
Confidentiality	—	x	—	x	—	x	x	x	5	1
Communication	x	x	x	x	x	—	x	x	7	4
Trust	x	x	x	—	x	x	x	x	7	4
Choice	x	x	x	—	x	x	x	—	6	4
Prompt attention	x	x	x	—	x	x	x	—	6	4
Basic amenities	x	x	x	—	x	x	x	—	6	4
Social support	—	x	—	x	—	x	x	x	5	1
Coordination	x	x	x	x	x	x	x	x	8	4
Finances ^a	x	x	—	x	—	x	x	x	6	2

^a The theme of finances is not a part of health system responsiveness; x = statements, — = no statements.

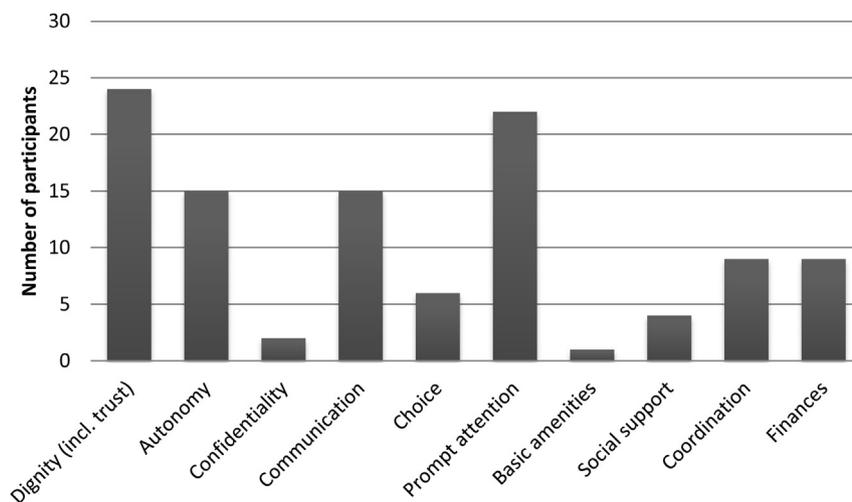


Fig. 2. Categories and number of participants selecting these as one of the three most important (n = 107).

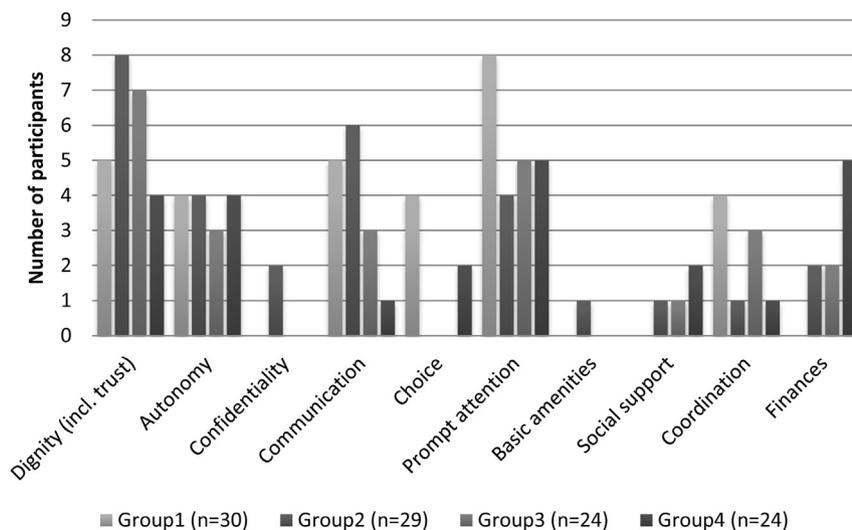


Fig. 3. Categories and number of participants selecting these as one of the three most important, per group (n = 107).

was hardly mentioned because it is completely fulfilled in Germany according to the participants, who neither reported very positive nor very negative experiences with it. For the operationalization of the responsiveness concept in Germany, this finding indicates that it might not be necessary to include the domain of *social support*.

Similar to *social support*, *confidentiality* was also hardly mentioned, albeit it was not felt to be totally fulfilled. Participants were able to share negative experiences with confidentiality but, as the results in Figs. 2 and 3 demonstrate, it was apparently not perceived to be as important as the majority of the other domains. This is rather surprising since security and confidentiality of personal data are subjects of controversial public discussion in Germany. Additionally, confidentiality was rated the most important domain by 19% of the German respondents in the MCSS, and only “prompt attention” was rated more often (38%) as most important (Valentine et al., 2008). Yet, Bramesfeld et al. (2007a) report similar results to our study: attention (an extended version of the prompt attention domain), dignity and autonomy were the most discussed and thus the most important domains. Confidentiality was the third least important domain, followed by social support and continuity. As the authors argue, the differences in the importance of confidentiality might be due to the differences in the study participants. While Valentine et al. (2008) conducted a population survey including healthy and ill people, the study by Bramesfeld et al. (2007a) as well as our study included exclusively ill people and people who had extensive experience with the health care system. Thus, a regular interaction with the health care system may lead to different priorities regarding the responsiveness dimensions.

The theme *dignity* broadly overlapped with the initial WHO domain. However, the terms “dignity” or “respect” were neither used by the participants during the discussion nor intuitively understood across all groups. Our results indicate that the domain *dignity* is relevant for the assessment of responsiveness in chronic disease care but that the wording should be revised, or operationalized using its subthemes, e.g. friendliness and empathy, for operationalization in Germany.

The themes *communication*, *prompt attention*, *choice* and *autonomy* again largely overlapped with the respective WHO domains. For *prompt attention* and *choice*, the desire for equal treatment especially between privately and statutory insured, was frequently expressed by the participants and thus should be considered in the operationalization of the responsiveness concept.

4.2. New domains

Supplementary to the WHO domains, two more themes were identified: *coordination* and *trust*. The theme of *coordination* consists of two aspects: the coordination of the individual course of treatment and the coordination of care across different services and providers. This is consistent with previous research on new approaches in chronic disease care, which defines coordination of care as a major goal (Busse et al., 2010). Additionally, the importance of chronic care coordination is visible in other questionnaires focusing on chronic conditions (Maeng et al., 2012; Schoen et al., 2009) and previous research that tested the responsiveness concept also led to similar results (Bramesfeld et al., 2007a). The original WHO responsiveness domains did not cover coordination. We thus classified this theme as an extension of the major domain “client-orientation” as it relates to the organizational aspects of care provision, as do prompt attention, social support, choice and quality of basic amenities.

The theme *trust* has not been covered by responsiveness questionnaires so far (Valentine et al., 2003). Yet, it has already been part of patient satisfaction instruments and a variety of scales measuring trust between patients and physicians exist (Bova et al.,

2012; Dugan et al., 2005; Zheng et al., 2002). The term “trust” in our analysis refers to the extent to which patients can trust their physicians to provide them with the best available treatment; this includes that no motive other than the patients’ wellbeing affects the physicians’ decision-making. Patients who experienced a lack of trust spoke about experiences where “ineffective” products or treatments were recommended to them as well as about potentially effective treatments they did not receive, e.g. due to the physician’s budget. With the latter example, participants expressed their belief that physicians are strongly influenced by health insurance funds and do not always have the possibility to provide their patients with the most effective treatment. Thus, although the theme of trust is related to “dignity”, it is possible that patients feel respectfully treated but still experience a lack of trust in receiving the most appropriate treatment. While the theme *coordination* is particularly related to the high and complex needs for the care of chronically ill, the theme of *trust* does not seem to be exclusively related to chronic disease care and might thus also be of relevance for less extensive users of health care. We suggest including trust as a distinct domain in the responsiveness framework and more specifically as an extension to the major domain “respect for persons”.

4.3. Limitations

The following limitations have to be considered in the interpretation of our results. The results are based on experiences with the German health care system. Specifics of the German health care system, e.g. a rather strong separation of outpatient and inpatient care, are reflected in the experiences of the participants and consistently in the results of this analysis. This has to be considered carefully when applying the results to other countries and health care systems. Additionally, we exclusively conducted focus groups with chronically ill people. The applicability of our results and especially the relevance of the new domains for less extensive users of health services still need to be tested. Furthermore, all participants lived in Berlin and its surroundings so their experiences might be different from the experiences of chronically ill people in other parts of Germany. For example, patients in Berlin have a greater choice of health care providers than patients in rural Germany. Nevertheless, it can be assumed that the expectations regarding health care are similar across different parts of Germany. We tried to overcome this limitation of varying experiences by asking the participants for both very positive and negative experiences.

5. Conclusions

In summary, our findings indicate that the WHO responsiveness domains are relevant to the chronically ill. The inclusion of the domain *social support* might not be necessary when operationalized in Germany as it seems to be completely fulfilled. However, the inclusion of this domain is certainly of relevance in other countries. In order to measure the responsiveness of chronic disease care comprehensively, the domains should be extended to include *trust* and *coordination*. Furthermore, some amendments to the original WHO domains are necessary for enhanced comprehensibility when they are operationalized in Germany, such as with the domain of *dignity*.

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